



The Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease

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Purpose of the Study

Develop and validate a theoretical model that describes the psychological and social effects of BeS and CBD.

Why?

- 1.If we understand the psychological and social effects of BeS and CBD we can tailor programs, education, and treatment.
- 2.If we understand the objectives, we can evaluate the effectiveness of the program.



Study Design

Phase 1

- Develop a theory-based model

Phase 2

- Qualitative research (interviews)

Phase 3

- Quantitative research (questionnaires)



Phase 1

Model is based on 4 theoretical concepts

- Health, Stress and Coping
- Psychosocial Adjustment to Illness
- Uncertainty in Illness
- Health Quality of Life

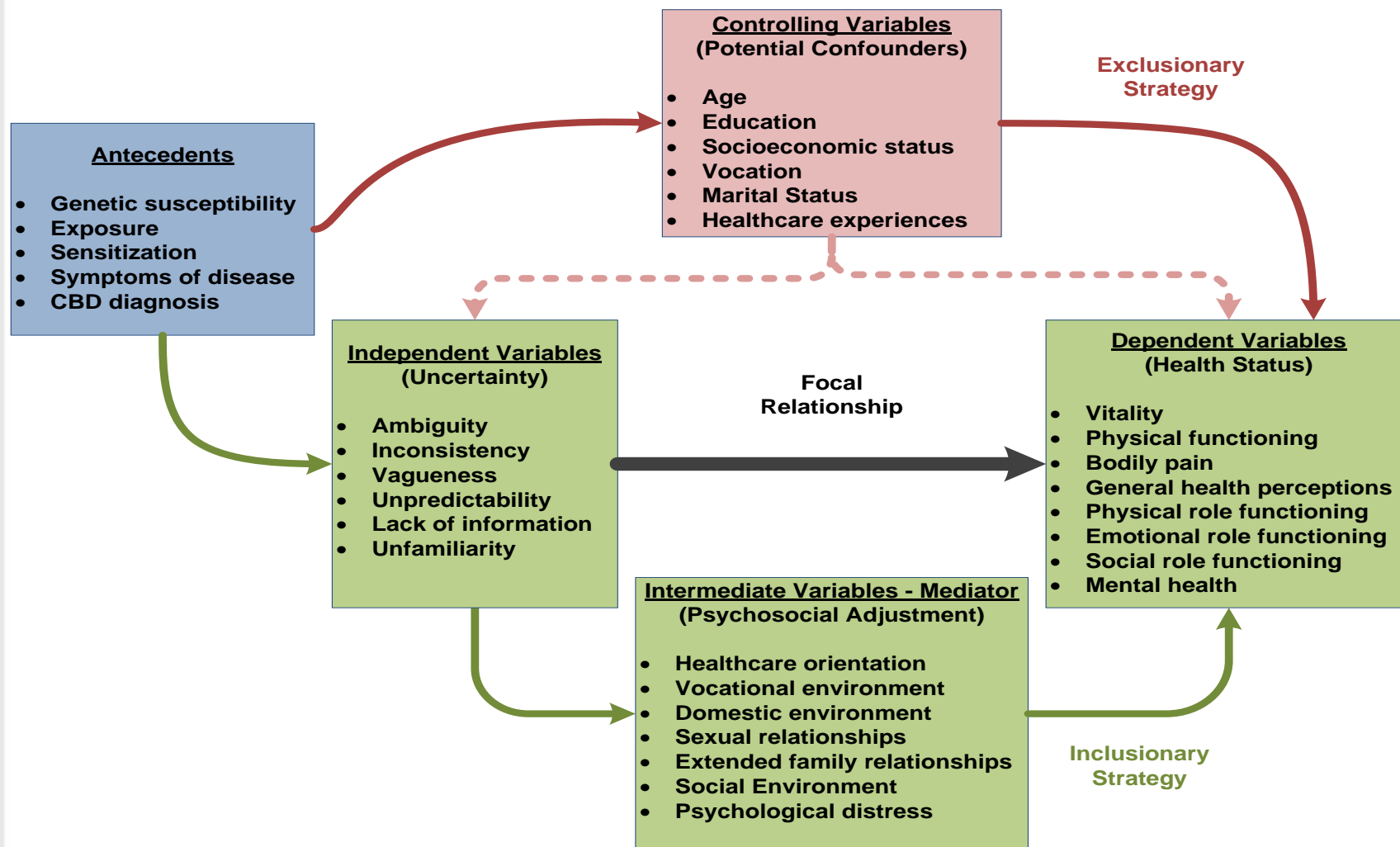


Figure 1: Conceptual Model of the Psychosocial Effects of Beryllium Sensitization and Chronic Beryllium Disease



Phase 2 - Methods

- Semi-structured, confidential interviews
- 13 participants
- 1-2 sessions each
- ~2 hours of interview data per participant
- Transcribed interviews
- Coded with QDA Miner®
- Identified categories & themes
- Compared results to model



Phase 2 - Results

Participants (n=13)

- From DOE sites in Oak Ridge, TN
- Mostly white, married, male, craft workers
- Some trade school or college
- Most still working
- Most had CBD (n=9)
 - 3 to 19 years w/ CBD
- Others were BeS (n=4)
 - 0 to 7 years w/ BeS



Phase 2 - Results

Participants described ambiguity, inconsistency, vagueness, unpredictability, lack of information, and unfamiliarity consistent with Michel's Uncertainty in Illness theory.

They also described how they adjusted to their condition in a manner aligned with Derogatis' Psychosocial Adjustment to Illness theory.

Uncertainty

When something is **ambiguous** it is open to more than one interpretation.

P3: My first blood LPT was borderline. If I had known what I know now, I could look at that and been like, okay, that's like being borderline pregnant.

Uncertainty

Inconsistency is when two or more things lack in agreement

P2: What's happening with some of the doctors they want to go back and do all the testing and then on a couple of people they are telling them 'no you don't have the disease.' Okay, you go through the Department of Labor and they say you've got the disease and now the Workers Comp Doctor is saying you don't have the disease.

Uncertainty

Vagueness means that something is not clearly understood or is not definitely known.

P6: I didn't like that feeling of not knowing, especially in the beginning. They were saying, 'I think you have an ear-nose-throat infection.' Then they wanted to blame it on stress. I said my job is fine, my home life is fine. I told them they were making me stressed and somebody needed to find out what was wrong with me.

Uncertainty

When something is **unpredictable** it is difficult or impossible to foretell or foresee.

P5: Well, I would say the worst part is not knowing. I pray about it and my faith is that everything is going to be alright. So I try not worry about the unexpected. But yeah, you think about it.

Uncertainty

Lack of information refers to an absence of data.

P7: Back then it was kept very quiet. I knew what I had, but I never had anybody talk about it. Then they started diagnosing all these other people that had it. Up until then it was kept very quiet.

Uncertainty

Unfamiliarity refers to situations that seem strange or that are not within one's knowledge.

P12: I'm walking in like I got out of general math and y'all's talking calculus. They're talking way over my head and I just kept coming down there and finally I got to learn what they're talking about.

Psychosocial Adjustment

Healthcare orientation addresses the participant's health care posture and whether it will promote a positive or negative adjustment to the illness and its treatment.

P8: I had a doctor and he passed away, so I just kind of let it slide for about three years. I went over there again just the other day, and that new doctor, was setting me up for another scan. He's really taken a lot of interest in me. So I think I'm alright, but you know it makes you wonder.



Psychosocial Adjustment

Vocational empowerment reflects the impact that a medical disorder may have on vocational adjustment

P1: Some of it may be joking or kidding, but you never know with some of the guys if it's really heartfelt. They don't just come out and say, 'you don't have to do this dirty job because you can't wear a respirator and I have to do it.' When you can't suit up anymore because of lung issues, you get the cushy jobs and they do the hard work.



Psychosocial Adjustment

Domestic environment is oriented toward illness-induced difficulties that arise primarily in the home or family environment.

P10: My wife's kind of wondering how much worse am I gonna get. Am I going to have to take care of you for the rest of your life? I know she stresses about that.



Psychosocial Adjustment

Sexual relationships provides a measure of any changes in the quality of sexual functioning or relationship associated with the participant's illness

P3: Personally speaking, I've had issues. In fact, that is one of my covered conditions under Department of Labor. You know there's treatment.



Psychosocial Adjustment

Extended family relationships measures any disruption or derangement in relationships with the extended family that arises with the illness experience

P10: It's hard to talk to people that don't work here. You have to go through the whole deal of explaining what it is. My brother, I told him that I had a disease, but it just never registered with him. He just looked at me real funny and didn't really know what to say.



Psychosocial Adjustment

Social environment reflects the participant's current social and leisure time activities and the degree to which the participant has suffered impairment of these activities as a result of their illness

P12: If you'd have asked me 10 years ago, what are you going to do for retirement? I'd have said hunting and fishing, but that ain't going to happen. Things change.



Psychosocial Adjustment

Psychological distress is designed to measure dysphoric thoughts or feelings that are a direct result of the illness

P3: Being diagnosed with beryllium disease changes your attitude about a lot of things. There were feelings of betrayal, of anger; just a wave of depression. Like, what does this mean?



Phase 2 - Results

Theme 1 – the Trailblazers

These Trailblazers were mostly craftsmen who were diagnosed with CBD and, out of necessity, became vocal advocates for sick workers. They helped shape the laws and regulations that are now in place to prevent CBD and to ease the burden on future workers who are unfortunate enough to develop BeS or CBD.



Phase 2 - Results

Theme 2 – the Rollercoaster Ride

P3: It's never a straight line with me. It's always a rollercoaster, up and down. When I have a bad day, when I'm having trouble breathing and aching all over and man, it's not worth it. I have to convince myself that it is. So it's, it's an ongoing battle.



Phase 2 - Conclusion

- It is appropriate to apply Uncertainty in Illness and Psychosocial Adjustment to Illness theories to BeS and CBD.
- The interview data was consistent with the model



Phase 3 - Methods

- Measure the psychosocial effects
- Nationwide survey DOE workers with BeS/CBD
- 4 questionnaires (demographics, MUIS-C, PAIS-SR®, SF36v2®)
- 3 methods of recruiting (BSGOR, SOMD, NJH)
- 126 participants (52 CBD, 74 BeS)
- 22% response rate
- Quantitative analysis

Phase 3 – Methods

1. MUIS-C Scale

- Absolute range 23-115, mid-range 69
- Mean score 63.7 (HIV)
- Mean score 74.8 (epilepsy)
- High score = bad

2. PAIS-SR® Scale

- Raw score range 308 – 466 (lung cancer)
- High score = bad

3. SF36v2® Scale

- Norm 50, SD 10
- High score = good

Phase 3 - Results

Table 3.3. Participants by disease status and Department of Energy site

DOE Site	Current Workers		Former Workers		Total	
	CBD	BeS	CBD	BeS	N	%
Y-12	7	15	7	5	34	27.0
Rocky Flats	3	3	8	8	22	17.5
Hanford	1	6	7	6	20	15.9
Kansas City Plant	3	5	2	10	20	15.9
Pantex	2	7	1	1	11	8.7
Los Alamos Nat Lab	2	0	4	2	8	6.3
Nevada Test Site	0	2	2	0	4	3.1
Idaho Nat Lab	0	0	1	2	3	2.4
Lawrence Livermore Nat Lab	0	0	1	1	2	1.6
Oak Ridge Nat Lab	0	0	1	0	1	0.8
Sandia Nat Labs	0	1	0	0	1	0.8
Total	18	39	34	35	126	100

Phase 3 - Results

Table 3.4. Results of the SF-36v2® Health Survey

Survey Component and Domains	Mean Score	
	CBD	BeS
Physical Component Summary	39.1*	43.2
Physical Functioning	40.8	43.2
Role Physical	40.9	43.7
Bodily Pain	42.4	45.0
General Health	39.1	41.8
Mental Component Summary	47.1	46.4
Vitality	44.6	44.5
Social Functioning	43.6	44.1
Role Emotional	42.5	44.1
Mental Health	48.2	47.3

Norm = 50.0, SD = 10

* p=.038, t-test (2-tailed)

Phase 3 - Results

Table 3.5. Results of the Mishel Uncertainty in Illness Scale–Community Form (MUIS-C) Survey

Disease Status	N	Mean Score	Standard Deviation
CBD	50	68.3	12.9
BeS	71	68.1	10.8
Total	121	68.2	11.6

Example Mean scores: Epilepsy = 74.8, HIV = 63.7

Missing=5; BeS=beryllium sensitization; CBD=chronic beryllium disease

Phase 3 - Results

Table 3.6. Results of the Psychosocial Adjustment to Illness Scale–Self Report (PAIS-SR®) Survey

Domain	Mean Score	
	CBD	BeS
Overall Score	433.7*	411.7
Healthcare Orientation	62.9	63.9
Vocational Environment	63.6**	59.5
Domestic Environment	63.4*	57.8
Sexual Relationships	63.7*	59.1
Extended Family Relationships	62.5	59.6
Social Environment	61.4***	58.3
Psychological Distress	56.3	53.4

* p=.02, t-test (2-tailed), ** p=.003, t-test (2-tailed), ***p=.04, t-test (2-tailed)

Phase 3 - Results

Table 3.7. Correlation matrix for SF-36v2® Health Survey, Psychosocial Adjustment to Illness Scale–Self Report (PAIS-SR®) Survey and Mishel Uncertainty in Illness Scale–Community Form (MUIS-C) Survey scores

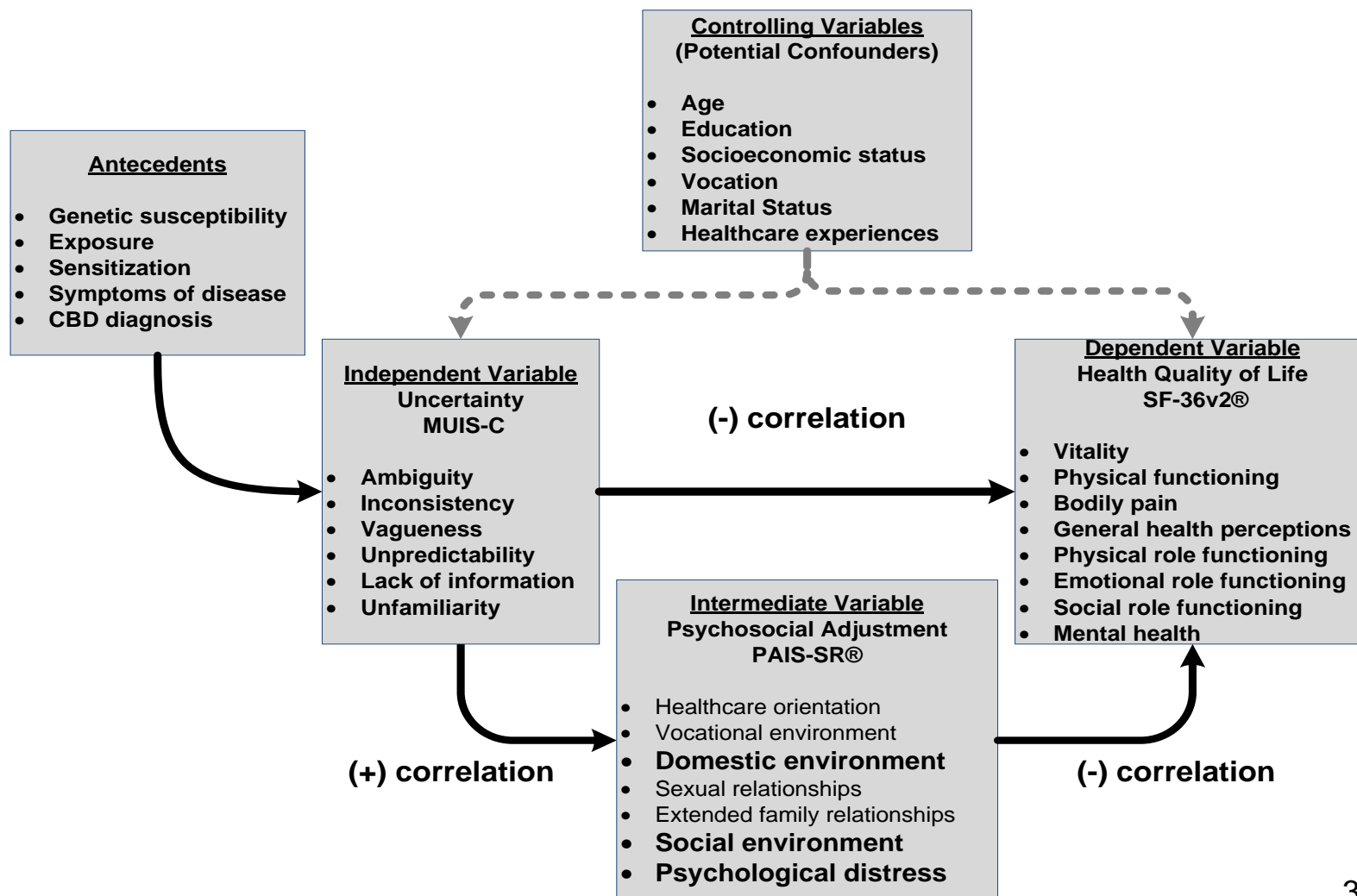
Disease Status		MCS	PCS	PAIS-SR®	MUIS-C
CBD	MCS	1			
	PCS	.26	1		
	PAIS-SR®	-.31*	-.24	1	
	MUIS-C	-.21	-.21	.62***	1
BeS	MCS	1			
	PCS	.33**	1		
	PAIS-SR®	-.45**	-.42**	1	
	MUIS-C	-.23	-.23	.59***	1

*significant at the 0.05 level (Pearson Correlation, 2-tailed)

**significant at the 0.01 level (Pearson Correlation, 2-tailed)

***significant at the 0.001 level (Pearson Correlation, 2-tailed)

Phase 3 - Results



Phase 3 - Results

Table 3.8. Multiple regression model to predict mental component summary scores

Variable	Unstandardized Coefficients		Standardized Coefficients	t	Significance
	B	Standard Error	Beta		
(Constant)	81.7	6.59	-	12.4	<0.001
Psychological distress	-0.48	0.12	-0.44	3.78	<0.001
Social environment	-0.56	0.17	-0.41	3.30	0.001
Domestic environment	0.40	0.14	0.36	2.84	0.005



- Psychological distress measures **dysphoric thoughts and feelings** that accompany the individual's disorder (anxiety, depression, hostility, reduced self-esteem, body image problems, and inappropriate guilt)
- Social environment reflects the status of the participant's current **social and leisure time activities** and the degree to which the participant has suffered impairment or constriction of these activities as a result of their illness
- Domestic environment is oriented toward illness-induced **difficulties that arise primarily in the home or family environment**. Assesses problems in adaptation experienced by the participant and their family unit in response to the participant's illness

[Derogatis 1990]

Phase 3 - Results

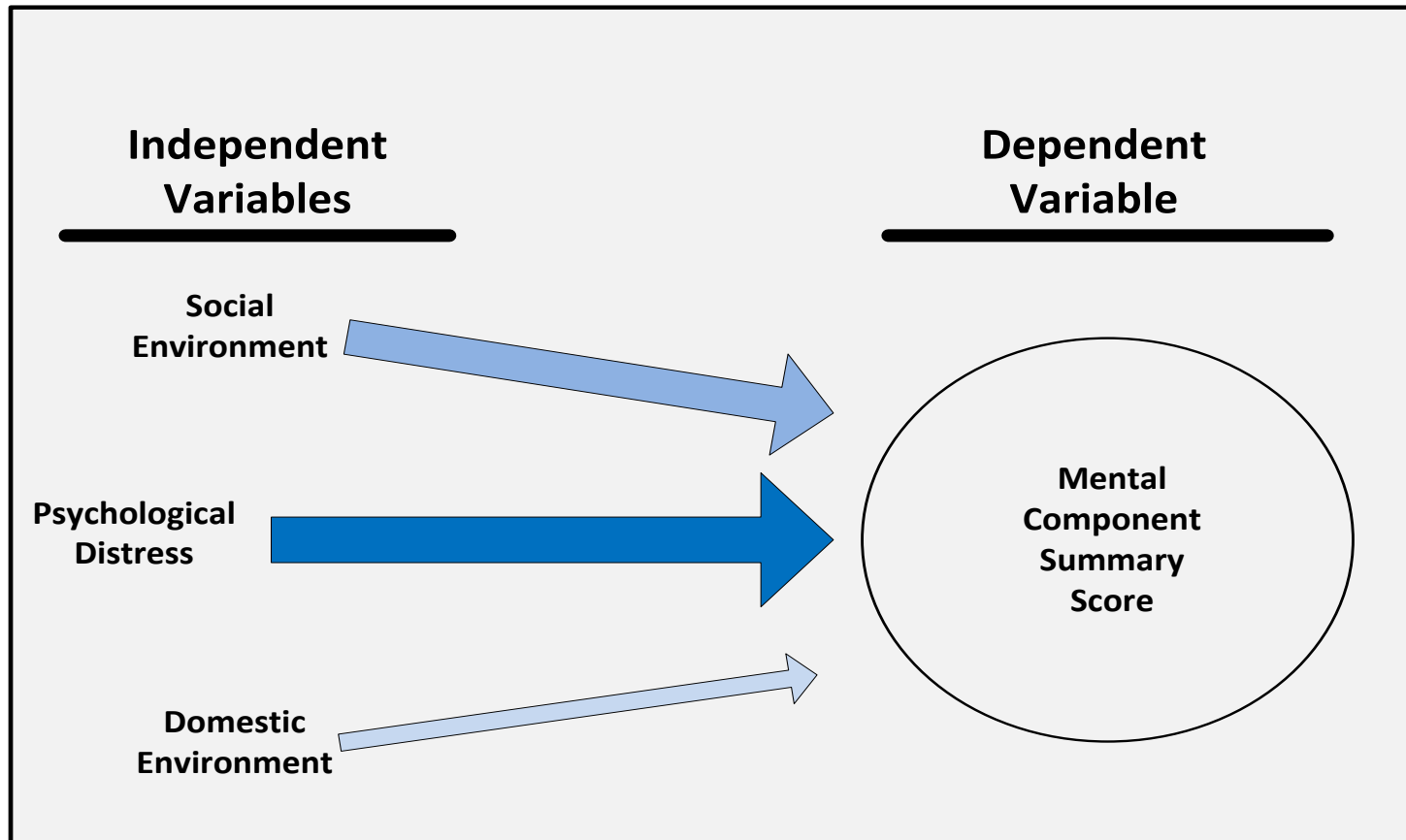


Figure 3.1. Multiple regression model path analysis



Phase 3 - Conclusions

- Psychosocial effects are an important component of BeS and CBD
- Results added validity to the model
- BeS may have as much impact on mental health as CBD
- Comparison of scores for all mental health scales indicated the same trend
 - Those with BeS had scores similar to those with CBD
 - Those with CBD may have progressed through the more psychologically damaging phase of BeS and are more resolved to their status with CBD



Phase 3 - Conclusions

- Implications for treatment and workers comp.
 - Compensation is linked to physical signs and symptoms of CBD while BeS is not compensable under most workers comp. programs
 - Insurance coverage for counseling and treatment for psychological distress and other mental health components may be warranted for those with BeS
 - Interventions should focus on coping strategies for psychological distress, social environment and domestic environment

Questions?



NASA, 2011